

Healthwatch Cornwall

A Good Death

February 2016





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Executive Summary

In January 2015 Healthwatch Cornwall (HC) published its findings on end-of-life care in its report *Place of Dying and End-of-Life*.

Feedback, subsequent to publication, from a number of provider organisations indicated that there were pockets of excellent practice occurring but that there was not a joined up approach; neither was there a commissioner with overall responsibility for strategic direction for end-of-life care.

The original report included a recommendation for HC to hold a conference to disseminate good practice and provide an opportunity for professionals to meet to comment on what is required for Cornwall to achieve excellence in this area.

The Cornwall Collaborative End-of-Life Group, which included multi-agency professionals, had been working to improve practice and were supportive of HC's proposal for this constructive and informative event.





Background and Methodology

The A Good Death Conference was held on January 29, 2016, at the St Austell Conference Centre. The conference was opened by Sarah Newton MP and this was followed by a number of presentations from health and social care representatives, as summarised below.

Jo Smith, End-of-Life Programme Facilitator Peninsula Community Hospital CIC

- Gold Standards Framework in Community Hospitals Programme

Rachel Newman, Consultant in Palliative Medicine and End-of-Life Care, Royal Cornwall Hospitals Trust

- Audit of 5 Priorities of Care

Jane Gibbins, Cornwall Hospice Care

- Hospice Care and the importance of joined up working

Dr Matt Boulter, GP Partner, The Alverton Practice, Penzance.

Chair, Penwith Living Well

- A GP perspective on good practice

Frances Tippett, NHS England

- Integrated Personal Commissioning budgets and End-of-Life

Mary Anson, Managing Partner, Anson Care Services

- A community perspective

Reuben Jenkins, Director, Carer's Break

- Time to Care - A Community Support Worker perspective

Felicity Warner, Founder Soul Midwives

- Soul Midwifery - Gentle Care of the Dying

Dr Maria Earl, GP Partner, Saltash Health Centre and Macmillan GP facilitator

- Lessons from the Wirral



The key messages from the presentations are shown in the next section and the presentations can be found on the HC website at:

<http://www.healthwatchcornwall.co.uk/a-good-death-end-of-life-presentation/>

Three workshops were held that focused on, and involved, interested parties. These were:

- 1) What is best practice at end-of-life for the patient?
- 2) What is best practice at end-of-life for the informal carer?
- 3) What does a joined up end-of-life pathway look like?

Key findings are shown in the next section.

The session concluded with an exercise on a potential End-of-Life Charter for Cornwall, with results for this shown in the next section.





Main Findings

Key messages from each presentation

Jo Smith, Peninsula Community Health CIC (PCH) - Gold Standards Framework in Community Hospitals Programme

This presentation outlined the accredited Gold Standards Framework used in community hospitals, which shows appropriate actions and care that needs to be taken as patients approach the last years and end of their life. These actions are colour coded for appropriate timings and allow for advance care planning, development of Treatment Escalation Plans and a resuscitation decision record. It is not always easy to predict when a person is entering the “end-of-life” stage or even when close to death - although this is easier. PCH also co-ordinate care in the community with GPs and district nurses.

Rachel Newman, Consultant in Palliative Medicine and End-of-Life Care, Royal Cornwall Hospitals Trust - Audit of Five Priorities of Care

There are five priorities of care at the end-of-life (in last few days) - recognise, communicate, involve, support, plan and do.

The audit showed that 48% of patients dying in hospital are only recognised as dying 48 hours or less before they actually die, but there was a wide variation in the amount of time a patient was in hospital before dying was recognised (maximum 50 days).

Patient wishes regarding hydration and preferred place of death documented in only 7% of cases, family wishes on same - 10% and 16% of time. Only 26% of the patients sampled had advance (advance not advanced - means in advance of loss of capacity) care plans. Several of these were simply that the patient had an existing ‘Allow Natural Death’ (do not resuscitate) Order in the community before admission.

There were good levels of medication prescribed against symptoms of pain, distress, nausea and vomiting and respiratory tract secretions but this could be improved if the end-of-life symptom chart was used more regularly for assessment, and agreed common Anticipatory Prescribing Guidance was used for prescribing. Care plans showed action for hydration and pressure relief in 80% and 67% of cases.

Treatment Escalation Plans and anticipatory prescribing were both introduced in 2015 but improvements in end of life care could be made if:

Staff were not afraid to record “needing end-of-life care”; there was more thinking earlier on in admission; wishes were discussed and recorded with patients as well as family; and pastoral care in the hospital was used more often. An action has been agreed to implement formal documentation of discussion and agreed outcomes with patients and family regarding the parameters of their care - to be developed via a Listening into Action event in March.



Jane Gibbins, Cornwall Hospice Care

- Hospice Care and the importance of joined up working

In her presentation Jane described the role of the Hospice. Patients can be admitted 24/7, usually with high complexity of need. There are multi-disciplinary teams involved in their care, with daily reviews and generally stays are below seven days. Stay gives patient time to have their crisis managed and to be supported, and sort out preferences and priorities for their end of life. An audit shows patients report vast improvement in their quality of life after a stay. As well as in-patient care, the hospice support care at home and in care homes, outpatient appointments for oncology and palliative care. They run a 24/7 support and advice line open to all professionals, patients and carers.

They do recognise challenges in the current system - increased demand versus capacity, absence of a substantive end of life lead in NHS Kernow, funding limitations, underused capacity of the day service which presents an opportunity and differences in governance and difficulties in inter-agency working. Their aspiration is to provide joined up care around the patient.

Dr Matt Boulter, GP Partner, The Alverton Practice, Penzance + Chair, Penwith Living Well

- A GP perspective on good practice

This talk explained some of the frustration from a GP perspective of not having access to care plans, the multiplicity of care plans and different documentation, and the pivotal role of GPs in managing end-of-life care in the community. The idea of the 'Just In Case box' was explained. This contains care notes, anticipatory medication and is kept in the patient's home.

Dr Boulter outlined plans to have a completely integrated IT system for patient records across all partners by 2020, which he leads on.

Frances Tippett, NHS England

- Integrated Personal Commissioning budgets and End-of-Life

Frances explained about budgets that have been used to support people with mental health issues and long term conditions, and are now available for people at end-of-life.



Mary Anson, Managing Partner, Anson Care Services
- A community perspective

This presentation considered the role of the social carer in respect of supporting the dying, with emphasis on the condition of dementia. It acknowledged that is often problematic to recognise end of life - people do stabilise and improve. It is particularly challenging if a person has dementia when their preferences cannot be expressed. However, feelings remain and matter most - love, nurture, warmth and safety - as seen in the Gladys Wilson video.

The emphasis then switched to unexpected death and the issues this causes. It can cause a 999 call out and ambulance, and dying in hospital against a person's wishes. If a person dies unexpectedly in a care home the coroner and police are involved and there is a post mortem. The body cannot be moved and the naked body is examined closely by police and photographed for forensic evidence. Doors are sealed to protect the crime scene, family and other residents are distressed, staff are anxious. The Care Quality Commission (CQC) and the local authority need informing. All of this shows lack of dignity for the person.

Reuben Jenkins, Director, Carer's Break
- Time to Care - A Community Support Worker perspective

This passionate presentation illustrated the importance of support in the community and the person's home by Community Support Assistants, as employed by Carer's Break. Reuben interviewed three of his staff, employed for their care and compassion, about what they had done to facilitate a better outcome for their clients that stemmed from the relationships they had built up.

Felicity Warner, Founder Soul Midwives
- Soul Midwifery - Gentle Care of the Dying

This talk explained the role and practice of Soul Midwives. They are holistic and spiritual companions - often from diagnosis - to the friend (dying person). They offer a non-medical, non-religious support to create a calming and dignified atmosphere and support the friend to do what they want or need to at the pace they set. They may sit and vigil at the person's bedside, hold hands, use gentle therapies to calm and ease fear.



**Dr Maria Earl, GP Partner, Saltash Health Centre and Macmillan GP Facilitator
- Lessons from the Wirral**

This presentation described the process gone through to improve end-of-life care. Successes included the development of Palliative and End-of-Life Partnership Group, a Hospice at Home Service, the adoption of Deciding Right, ongoing education and training, and the development of an End-of-Life Charter, which was shared and worked on during the afternoon workshop.

There was other work in primary care, GP Practices participating in the Gold Standard Framework 'Going for Gold' Accreditation, ongoing Anticipatory Prescribing and ability to use electronic medication sheets. The group were also involved in Acute Hospital end of life care and the Hospice, improved access to specialist palliative care teams and encouraging care homes to complete a service improvement programme. There was also involvement in Dying Matters events and training for domiciliary care providers.





Main comments from the workshops

Workshop 1 - What is best practice at end-of-life for the patient?

Patients would want (in descending order of popularity):

- 1) To be heard/listened to
Family or known people present
- 2) Pain free/symptoms managed
Co-ordinated/streamlined services
- 3) Caring and compassionate staff
To be treated as an individual
To feel safe
- 4) Treated with dignity
A single care plan
To do normal things

What is already in place - most commented on:

Marie Curie Nurses
Community, Hospice and Hospital Palliative Care Teams
Volunteers
24-hour advice from hospice/specialist knowledge
Hospice Care
GPs and District Nurses, GP home visits
Pain relief

But others noted include night sitters, medication at home, hospitals, nurses, Just In Case box, anticipatory prescribing, TEP's (Treatment Escalation Plans), ANDO's (Allow Natural Death Order), Care plans, and Living Well.

Positively, it was noted that there are pockets of great care, people who want change, and goodwill to improve services.

However, comments also noted a risk adverse system, duplication, fragmentary statutory services, and personal information not being logged.



What is missing? (in order of popularity):

24/7 access to electronic care plans, TEP's (Treatment Escalation Plans), DNAR's (Do Not Allow Cardiac Pulmonary Resuscitation), ADRT's (Advanced Directive to Refuse Treatment) for all care staff, Out of Hours GPs, Ambulance Services, palliative care, district nurses and carers.

24 hour community nurses

Hospice at Home

Multi agency working, meetings and planning, with mutual respect for each other

Improved communication between clinicians and carers

A common care plan

Co-ordinated working

A patient "ambassador" who can ensure care is patient focused and agrees with patient's wishes

Also mentioned were single point of access for everyone for advice; funding for spiritual/pastoral wishes, enough hospice beds if patients can't stay at home, responsive and flexible involvement of Community, Hospice and Hospital Palliative Care Teams or Macmillan; 24-hour access to medication; equitable access across county; out of hours death verification; specialist care at home capacity and inspirational leadership.





Workshop 2: What is best practice at end-of-life for the informal carer?

Carers would want (in descending order of popularity):

- 1) To know who to call for support, 24 hours a day
- 2) To be listened to
- 3) Respite

Also noted were advice on what happens next and what is expected of me, not to be seen as a nuisance and emotional support.

What is in place? Most commented on:

Macmillan Support/Marie Curie/Carers Support groups

GP's/Hospices/Soul midwives

Community Pharmacy/Living Well/District Nurses and Community Matron/PCH
Care Plans and Gold Standard/Carers Break/Age UK, Rotary and Lions Club

What is missing?

Access to information about services including Voluntary and Community Organisations

Cross sector and integrated working, including communication and record sharing

Communication with carers

Out-of-hours nursing

Workshop 3: What does a joined up end-of-life pathway look like?

Shared electronic access to a single care plan and/or patient passport

Communication between clinicians/ patients/ family/ carers

24/7 support and community nursing

Early conversations with patients about their wishes

Single point of contact for patients and providers

End of Life Charter

Communal documentation

Commissioning a pathway - not individual services

GP practitioner group

Unified education



Charter Exercise

The audience was asked to rank potential Charter statements, edit and comment. Eight out of 12 statements showed a mode of 1 (most preferred) and a median of less than 5. These are shown here in order of median scores:

- 1) Support by skilled, caring and knowledgeable staff that recognise your situation and who work together to co-ordinate and manage your care (NB caring added as edit)
- 2) Care which includes what you eat and drink, control with your symptoms, and support with your emotional, social, cultural and spiritual needs
- 3) That you, and others important to you, will be treated with compassion and respect towards the end of your life
- 4) That if you wish, those who are important to you are involved in decisions about your care and treatment
- 5) The support of trained staff who will help you to think and plan ahead, if you want to discuss your preferences and wishes for your care
- 6) With your permission that plans, if you have made any, are shared with those involved in your care, so that your wishes may be fulfilled
- 7) The possibility that you may die within the next few days or hours is communicated clearly and sensitively, to you and those who are important to you
- 8) Support to help keep your independence as long as possible by caring staff respecting your dignity and sense of control throughout your illness

Comments

Put them in a wheel - hard to rank and different ones more important at different times.

They would be better as “I statements” e.g. 1 would read - I want to manage my care and have support from skilled and knowledgeable staff to co-ordinate and achieve this.

There should be a patient, staff and public consultation on this.

Charter needs to be owned by all.

Potential Charter inclusions

My choice of place to die is acknowledged and made to happen wherever possible.

My place to die is not overridden or delayed by addressing risk unreasonably - such as awaiting pressure relief or transfer.

Me and my loved ones are kept informed about what might happen, symptoms and changes, in order to reduce the fear and anxiety.



Conclusions

There were a number of clear messages that came out of this conference but what was extremely heartening was the goodwill and willingness from all to make improvements to the current system - to the benefit of the patient and their loved ones.

Key messages

Patients want:

To be heard/listened to

To have family and friends present at end

To be pain free and have symptoms managed

To have co-ordinated, streamlined care

To be treated as an individual and with dignity

To feel safe and to do their normal activity as long as possible

To have and be involved in a single care plan

What needs addressing in current system or is missing?

24/7 access to electronic care plans by all parties involved in care and including the patient

24 hour community nursing

Multi agency working, meetings and planning around patients, where there is mutual respect for all parties

Better communication between clinicians/patients/family/carers

Co-ordinated working - Communal documentation

Single point of access, 24/7, for advice on clinical matters or available services (including voluntary and community sector) that all parties can access

Early conversations about end of life wishes, which could include public health awareness raising on end of life planning

Equitable access to provision across the county and consideration of rurality and transport

Flexible access to Community, Hospice and Hospital Palliative Care Team/Macmillan

Out of Hours death registration

Specialist Care at Home capacity

A change to commissioning arrangements so commissioning is for pathways not services

Development of a Charter, after due consultation with staff, patients and public, that all sign up to.



Recommendations

- 1) A substantive End-of-Life Commissioner to be appointed.
- 2) Commissioner and Cornwall Collaborative End-of-Life Group (CCEOLG) to coordinate and organise county wide multi-agency working so it can be effective in planning and co-ordinating care around the patient. This may require a resource investment and membership changes to the CCEOLG (which was set up for a different purpose).
- 3) Electronic Care Plan accessible to all, which preferably should be able to be held on patient devices such as smart phones or tablets.
- 4) Serious consideration of commissioning more flexible community nursing and specialist palliative community nursing that can cover 24/7 and respond to demand.
- 5) Develop and resource the Hospice advice line so it becomes the single point of access for information on patient care and available services and provides carer support.
- 6) Task group to develop communal documentation for all service providers that can simplify the system and avoid duplication - to be in place by April 2017.
- 7) Commissioning process to be reviewed so that a care pathway is funded - not individual services - which should reduce duplication in system.
- 8) A review of cross sector practice to establish where duplication is and how it can be avoided so funds can be reinvested in needed services.
- 9) A review of care home and hospice provision to see if it meets future demand.
- 10) A full professional, patient and public consultation on a Charter using work reported here as a starting point.
- 11) Consideration for developing a cost effective system for out-of-hours death registration.
- 12) Public education by Public Health on end-of-life planning.
- 13) A professional commitment/strategy to encourage early planning of end-of-life wishes and appropriate recording so they can be acted on.



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